

**The National Citizens' Coalition for Nursing Home Reform,  
presented by Elma L. Holder, Founder**

The National Citizens' Coalition for Nursing Home Reform is grateful for the continuing efforts of this Committee to advance quality of care for residents in nursing homes. Although we are here today to talk about the progress of reforms, it is critical that we acknowledge those thousands of residents and their families who are suffering today from neglect and care that fails to meet national minimum standards. Most progress in regulatory reform, however important, does not answer the problems of today's residents. The consumer sense of urgency for change is well-founded and grounded in the reality that regulatory change is always painfully slow.

It has been NCCNHR's privilege to present testimony, information and ideas to many outstanding senators who have actively supported nursing home reform since 1978. We applaud Senator Grassley's determination to hold the Health Care Financing Administration and the nursing home industry accountable to the public.

Because we have monitored regulatory activities of the Health Care Financing Administration for almost 25 years, we've seen a lot of initiatives come and go. Regardless of serious questions still remaining about how successful the present Initiative will be, we can say positively that we've never seen any initiative tackled by federal regulatory staff with such enthusiasm, even in the face of a small staff, determined by budget considerations. Although we have and will continue to be critical of some of HCFA's misguided activities, we have the utmost respect for the efforts of Nancy Ann DeParle, HCFA Administrator, and many of her staff members. DeParle, unlike most previous Administrators, has been exemplary in her outreach and willingness to listen directly to consumer views.

NCCNHR and other consumer groups are usually critical of government agencies because they move far too slowly. However, we have recognized since last summer that some of the serious problems and questions raised about and by the Initiatives surfaced because HCFA moved forward, sometimes beyond their control, too quickly. Soon after the July 1998 hearing and the President's Initiative was announced, important time should have been set aside for direct discussion and planning by all interested parties about what activities should be conducted that would make the fastest and most solid difference for residents. The nursing home system is entrenched; systemic problems do not change overnight.

NCCNHR's evaluation of the state of nursing home conditions and the 1998-99 Nursing Home Initiatives comes from several sources. Most importantly, we listen carefully to hundreds of family members, residents, consumer advocates and nursing home staff who have direct experience with both receiving and giving nursing home care. We talk to state regulatory agencies and incorporate their reaction and ideas. And, we are in regular contact with staff at the Health Care Financing Administration charged with the responsibility of implementing and overseeing the Initiatives.

Although NCCNHR has strong questions about the future outcome of the Initiatives, it is essential for everyone to acknowledge that it's too soon to tell for sure what lasting and widespread effect they will have on the actual care and services received by residents. For this reason, the Health Care Financing Administration simply must continue to apply extensive staff resources towards the Initiatives. HCFA also needs much stronger coordination of the Initiatives and any future endeavors.

To achieve this oversight and coordination, NCCNHR recommends that a highly-qualified person, experienced with nursing home issues, be appointed to serve as a special adjunct to DeParle, working exclusively to oversee the Initiatives.

Furthermore, NCCNHR contends that stronger, week-to-week oversight of HCFA activities is in order to see that this Initiative doesn't slip and that implementation actually results in changes in nursing home conditions. NCCNHR recommends the appointment of a special task force at the Secretary's level, composed primarily of a qualified, experienced research team, as well as representatives from the Office of the Inspector General (OIG), the General Accounting Office, (GAO), and the Justice Department.

NCCNHR urges Congress to increase U.S. Dept. of Health and Human Services/HCFA funding to support these oversight activities as well as current and additional activities to strengthen enforcement.

#### Overall Stronger Enforcement is Still Critically Needed

A recent General Accounting Office report gives, yet again, a bleak picture of nursing home life. The GAO reports that one-fourth of the nation's nursing facilities (approximately 17,000) continue to have deficiencies causing actual harm to residents or placing them at risk of death or serious injury. This affects approximately 400,000 nursing home residents. If 40 percent of facilities continue to repeat their deficiencies, this affects as many as 160,000 residents. These numbers are staggering, and would be so even if there were far fewer residents affected. Based on direct day-to-day confrontation of serious problems, consumers and ombudsmen would argue that these numbers represent only the tip of the iceberg, because survey and enforcement programs are so weak. *(Additional Steps Needed to Strengthen Enforcement of Federal Quality Standards, General Accounting Office, March, 1999)*

The Nursing Home Initiatives must continue, but must be bolstered by even stronger enforcement measures. Only then will we see the likelihood that protections and quality care directives in the national law will actually be achieved.

One of the most important pieces of the Initiative is still a mystery to consumers - the Federal Monitoring System (FMS). HCFA has reportedly completed 41.12 percent of 805 projected oversight surveys. We understand that there are 9 workgroups completing their tasks; however, consumers are eager to learn more detail about what HCFA is finding in the states. Consumer groups and ombudsman programs frequently report on the weakness of their state enforcement program. Even when serious deficiencies are found, enforcement action is missing.

The Regional Offices of HCFA offer another source of complaint from state agencies, surveyors, ombudsmen, and others. Although there are some good reports of strong oversight and enforcement positions by regional offices (such as Region II based in New York), many participants in and observers of the enforcement system find them often ineffective and obstructive. They are definitely considered inconsistent, as are the state agencies. **NCCNHR recommends** that a full study be conducted so that the effectiveness of the regional offices can be fully determined and needed changes made.

If the state agency always imposed quick remedies, this would be a strong deterrent to poor care in facilities. One of the impediments to this is the current Informal Dispute Resolution (IDR) process which was fought for and won by the industry, despite NCCNHR and other organized consumer protests. According to HCFA regulations, the states must offer facilities an opportunity to dispute cited deficiencies upon the providers receipt of the official survey report, HCFA-2567. If they request it, providers can refute cited deficiencies after any survey.

We were certain the industry and its attorneys would urge facilities to dispute deficiencies wholesale, and they have. If a provider is successful during the IDR process the deficiency citation can be deleted and any enforcement action(s) can be rescinded. Of course, residents, their families, and advocates are not allowed an opportunity to participate in, or to challenge this dispute, although the provider can have

legal representation, which many do. Although a state may include ombudsman participation, it is not required.

Residents remain without supportive representation. The IDR process illustrates another reform needed in the enforcement system. **NCCNHR recommends that** Congress call for a study of the IDR by the General Accounting Office or Inspector General's Office to determine what explicit effect it has had on enforcement.

Furthermore, consumers seriously question that nursing homes can continually tie up enforcement proceedings through their numerous appeals. One of our consumer groups, Advocates for Nursing Home Reform in Austin, Texas, asked us to relay the proposal that nursing home provider appeals be limited. The serious shortage of administrative judges to quickly process appeals also continues and should be resolved.

NCCNHR agrees with Toby Edelman of the National Senior Citizens Law Center that the new draft of enforcement provisions in the State Operations Manual must be supported and fully implemented so that the federal enforcement system will undergo needed improvements. Chapter 7 of the SOM contains instructions for imposing remedies on noncompliant nursing homes and includes enforcement consequences on States with inadequate survey performance. Though we are eager to get the regulations completed, we must admit that receiving a copy of the SOM from HCFA three days before the comments were due, last Friday, September 17, was disturbing. This blunder typifies bureaucratic delay that consumers often must deal with.

The bottom line is this: We now have better regulations on the books for aggressively pursuing enforcement in substandard facilities. Consumers are realistically and rightfully asking why enforcement is the exception, rather than the rule?

### Staggering Survey Schedules

The one change we hear about most is that states are beginning to make some surprise visits during the night shifts and on weekends. We applaud this important effort, although it will need to be monitored carefully by HCFA. For example, I was recently told by a local ombudsman that in one state the surveyors began the survey at 4:00 in the afternoon and left the facility shortly after 5:00, counting that as their "evening tour." Also, consumers report that some states still view these initiatives as "advisory" and are not staggering survey schedules.

Still, we are gratified to learn of Nelson Baugh's good experience with his facility's survey in Georgia and reported this morning. We are also pleased to report another example from one of our Louisiana members who gives high praise for such a survey in her community. Mrs. Alan (Freddie) Pincus states in the attached copy of a letter to Nancy Ann DeParle:

From January 19, 1999, through the 25<sup>th</sup>, a local team of surveyors plus two HCFA surveyors started an annual survey that usually occurs in June. They worked some evenings and through the weekend.....they missed very few of the egregious problems...

Ms. Pincus explained that this was a facility where the nurse call system had worked only intermittently since 1990. Linens had been in short supply since 1992. She had begun to think the "surveyors were blind."

NCCNHR and its members agree with the Pincus sentiment: "I sincerely hope this type of survey is not

just a one-shot ray of hope for the residents." Although this survey change cannot be too popular with many state agency staff, it is essential for them to conduct such surprise "untimely" surveys so that the industry will have additional pressure to comply with standards - twenty-four hours a day, seven days a week. No doubt, the most serious problem for residents is the lack of nursing staff available to give care on evenings, nights and weekend shifts. Regrettably, frail, disabled and ill residents do not miraculously get better when the evening or weekend shifts begin.

Nursing assistants, particularly from unions such as the Service Employees International Union, continue to report that nursing homes somehow seem to know approximately when the survey is to be held. According to nursing assistants and family members, it is not unusual for a facility to hire extra staff only for a spell of time close to and during the survey. At a public meeting of union staff attended by NCCNHR in the fall of 1998, one nursing assistant stated, "the best 3 days of my working year are when the survey team is there, for I know that then we'll have the extra staff needed to care for all our residents." She was cheered by other assistants in the room.

One of our members recommends that survey teams need to come from another region where they do not know the management of the nursing home. In many areas, it is certain that nursing home surveyors and facility administration do become cozy over the years. Evidence of that fact is that so many surveyors retire or leave their jobs especially to go to work for the nursing home industry. Conversely surveyors may come from the industry.

#### Increased Sample Size for Nutrition, Dehydration and Pressure Sores

**NCCNHR joins others in recommending** that states be given sufficient survey budgets to increase the survey sample size. Survey teams should also consistently use valuable MDS information about residents to enhance their sampling process.

Sampling in the survey process is inevitable in a system with limited funding. However, one of the most serious dangers in sampling is that a single resident being gravely neglected and/or abused could be missed in the survey process. This is counter to one of the greatest protections promised by the National Nursing Home Reform Law, that "each resident," is to receive quality care, quality of life, and maintenance of individual rights. Dr. Andrew Kramer, University of Colorado, has testified to the importance of a larger sample twice before this committee. Consumers agree.

It is especially important for surveyors to be well-trained and always highly-motivated to identify those individual residents who may not be getting service. One of the best methods for achieving this goal, is that surveyors be particularly attentive to reports of day-to-day problems shared directly with them by residents, family members, ombudsman staff and volunteers, and citizen advocates familiar with the facility.

#### Complaint Investigations

Although we support HCFA's directive to the states to investigate any complaint alleging harm within 10 days, we understand that several states are resisting this measure because of the lack of staff resources to carry it out. In fact, one HCFA regional employee publicly stated at a Maryland State Nursing Home Task Force meeting, that HCFA has "backed off" of this initiative and is not requiring states to implement it.

The timely investigation of complaints is essential. We must determine as soon as possible how much an effective complaint investigation system actually costs, so that HCFA's budgeting for the states will be

sufficient and states can be held accountable. HCFA is supposed to be reviewing current state practices as well as planning to give funds to a private agency for a major resource project. In fact, work by NCCNHR is included in one of the proposals before HCFA.

For years there have been widespread reports of the failure of state licensure agencies to substantiate valid, serious complaints made by residents, family members, ombudsmen and others. HCFA simply must take advantage of consumer information about the dismal failure of most complaint investigation programs. For example, family members from Virginia and Connecticut report serious complaints of abuse and neglect that have been dismissed in the past year despite these Initiatives.

**NCCNHR recommends that** each state develop an active advisory group of residents, family members, consumer advocates and ombudsmen to assist it in improving its complaint investigation system. HCFA should do the same at the national level as they develop State Operations Manual (SOM) instructions on how to determine inadequate survey performance.

Private investigators working for nursing home lawyers are notoriously skillful at finding serious problems based on family reports of poor care. HCFA and the states should take greater advantage of such professionals by regularly involving them in surveyor training.

If more complaints were handled quickly and thoroughly with necessary changes made to resolve problems - giving consumers effective recourse for their grievances - family members would have fewer reasons to pursue legal help.

We are heartened that HCFA will be funding the study of the states' complaint investigation programs; however, there is an abundance of information available that should be utilized in immediate HCFA reforms. For example, the use of quality care indicators in complaint investigation should prove useful to survey agencies as well as ombudsmen, if the information is made available to them.

#### Propose Civil Money Penalties (CMPs) for "Each Instance"

NCCNHR, representing residents and consumers, has recently intervened in litigation filed in federal court by the American Health Care Association against the U.S. Dept. of Health and Human Services. AHCA challenges the per instance civil money penalty rule arguing that HCFA did not have statutory authority to promulgate a rule. Further, the industry challenges HCFA's authority to establish this additional remedy under any and all circumstances.

Surveyors report they are using this proposal, but only for serious violations, as they were taught in training. **NCCNHR recommends** use of per instance CMPs for less serious violations as a deterrent effect to continuing poor care. Advocates everywhere ask, "How can enforcement happen if CMPs are not actually applied and collected?"

#### Poor Performing Nursing Homes and Nursing Home Chains

We understand that the part of the State Operations Manual dealing with poor performing chains is still under development and not included in the latest September 1999 draft. Consumers and ombudsmen are adamant that something must be done to consistently identify serious problems and take action against corporate chains. A serious problem facing families and advocates is that they have to contend with corporate decision-makers sometimes many states removed from their communities.

NCCNHR supports the ability of HCFA to enhance oversight of poorly performing facilities at the "G"

level. The June 30, 1999, General Accounting Office report (*HCFA Initiatives Improve Care but will Require Commitment*) gave ample evidence that surveyor citations were well-written and accurate, and showed that in 98% of their sample study, actual harm had occurred to one or more residents. HCFA should implement the expansion of the definition of poor performing facilities to include "G" level deficiencies that designate harm to one or more residents.

#### Criminal Background Checks and Worker Identification

Consumers have supported the initiative to require criminal background checks for all nursing home workers.

NCCNHR has endorsed the Kohl-Stark Patient Abuse Prevention Act. As now revised this proposed legislation would provide some due process for workers and also protect nursing home staff from bearing the cost of such checks. A National Abuse Registry, if implemented effectively and consistently, would address the issue of abusive workers crossing state lines.

One long-term advocate, Marie Wisdom from Advocates for Nursing Home Reform in Austin, Texas, recommends that every nursing home worker be required to wear a name tag which includes their picture, name, and thumb prints. She notes that government agencies, such as the IRS requires workers to wear them. Why not in nursing homes so residents, families, ombudsmen and others would always know who they are dealing with, whether the care is good or bad?

NCCNHR, the unions and others have been urging HCFA to require facilities to post the working staff roster on every shift so that families and residents will know who is there to care for them. This can also be used to determine the level of staffing on any given shift. **NCCNHR recommends** that the Senate Special Committee support this proposal.

#### Develop Better Management Information Systems

According to our discussions with researchers assisting HCFA with this Initiative, HCFA has not budgeted the necessary dollars to make sure that data systems are developed in a way that will assure that a quality assurance system will really work.

The MDS/QI System, a key to quality assurance, will also fail to support quality assurance unless HCFA creates an accurate, reliable, integrated data system.

HCFA needs to collect and report on information and results of the Informal Dispute Resolution system in each state; nursing home appeals and their results; and the number of citations assessed and collected. It is also essential for HCFA to provide information about the enhanced monitoring of special focus facilities, federal oversight surveys, and state complaint investigation findings. What did they learn and how can the information be applied to assure changes in the system?

Expenditures of public funds by industry should be more carefully monitored. A key is maintaining the integrity of the Medicare/Medicaid cost reports. The advent of the Prospective Payment System (PPS) threatens the very existence of cost reports for Medicare because payment is predetermined. However, since there are no prescriptions for how the money is spent under PPS, **NCCNHR recommends the following:**

Require mandatory federal uniform cost reports for both Medicaid and Medicare with core elements and common definitions. States would be able to add on other elements as needed. This approach would

allow HCFA, providers, and consumers to understand how money is spent and to compare the results with quality outcomes through the Minimum Data Set/Quality Indicator system.

#### Survey Information Available on the Internet

The provision of survey information through a HCFA website is a starting point, particularly for uninformed consumers. Still, knowledgeable consumers know that the survey information is only as good as the survey process and survey reports; therefore, **NCCNHR recommends** that this warning be given to consumers in a message up front in the survey report. Also, information is not put on the site in a timely manner, especially if the new survey information is replacing a deficiency-free report. In response to consumer complaint calls, NCCNHR regularly turns to the HCFA website to look at the survey results, often finding that they are over a year old. States must post survey information quickly after a survey, for we know that the quality of care can change quickly and dramatically, especially because of high staff turnover and frequent staffing changes. Nursing home care can be heavily affected, either to the good or the bad, by a change in any key member of the facility administration or a change in the number of staff.

1997 data contained in the 1999 American Health Care Association data book, divulges the following staff turnover rates: Administration, 21%; Director of Nursing, 32.5%; R.N., 50.6%; LPN, 51.3%; Certified Nursing Assistant, 93.3%; Department Heads, 32.9%. (Source: Buck Consultants Survey of managerial, Supervisory and Staff Positions in Nursing Homes, 1997.) An American Health Care Association staff member stated that they expect the 1998 and 1999 turnover rates to increase.

Since the 1980's we have advocated for HCFA to provide facility ownership information for consumers. Residents, their families, ombudsmen, advocates and others need to have specific addresses and telephone numbers of owners, individual and corporate, so that they can approach them to report serious care problems in facilities.

NCCNHR is pleased that HCFA will be conducting a pilot study using a NCCNHR postcard model to obtain evaluative information from people who visit nursing homes on a regular basis. Two states will provide residents, family members, staff, and other visitors the chance to complete a postcard check-off list to return postage-free to a designated agency. If this mechanism proves useful for consumers, it could provide valuable information to help identify facilities that may need to be looked at more closely. If adopted nationally, a system must be in place to support the use of this information.

#### Abuse Intervention Campaign

HCFA deployed considerable resources in this Campaign; however, some of the staff assigned to this effort were virtually inexperienced in nursing home care issues. NCCNHR contends that HCFA made its biggest mistake when it failed to call a group of all concerned parties together to plan a strategy, before initiating its own hurried plans. Time will tell whether or not the resources put into the new poster campaign will actually yield results. NCCNHR has advised HCFA since the beginning that the posters could be most valuable "out in the community." People can learn about ways to detect and report neglect and abuse before they use or visit a facility. We are still urging HCFA to use the posters in other sites such as senior centers, area agencies on aging, libraries, adult day care, hospice programs and public transport vehicles. It is our opinion that only good facilities will helpfully display the new posters. They will want to know if neglect or abuse is occurring.

It is good that HCFA has made revisions and is re-issuing its video and new written information to help consumers in their search for long term care. For sure, an educational campaign is only one small part of

a larger picture of needed reforms, but these efforts are worthwhile.

HCFA is speaking the right words. Consumers can not quarrel with the motto HCFA has adopted in its new public education materials. "Enforcement assures quality; Education understands quality; and Empowerment demands quality." Although many of HCFA's Abuse Prevention Campaign materials are under an evaluation period before completion, they are useful and definitely reflect the public interest.

We know that this is the first time in history HCFA has actually attempted such a public endeavor. The consumer video, graphically presents a rosie picture not seen in most typical nursing homes, but it does state very strong language about HCFA's new stance to prevent, detect, and take action against abuse. It will be helpful, as accessible, to new nursing home consumers, and, if nothing else, will provide a tool for consumers to help hold HCFA accountable for what it proudly and strongly claims it will *not do*:

**HCFA claims it will no longer tolerate nursing home neglect and abuse.**

One thing is certain, the Campaign has caught the attention of the industry. For the first time, the for-profit industry has initiated a national game plan of its own against neglect and abuse, mailing all its members a set of materials on abuse prevention training developed and available years earlier by the Massachusetts industry association. Regardless of the fact that the American Health Care Association took a route (foolish in our opinion) of advising its members not to use the HCFA poster, the association has at least been forced to respond publicly to what our membership believes to be serious, widespread problems with abuse and neglect affecting thousands of residents. Industry always appears to act on the assumption that its image precedes good care. Consumers know that image follows good care.

#### Strengthening the Ombudsman Program and Advocacy Efforts

NCCNHR recommends that the Committee continue its efforts to reauthorize a strengthened ombudsman program, another one of the Presidents' Initiatives.

State and local ombudsmen are now being used by HCFA to provide input to the public education campaign. HCFA and ombudsmen have held discussions on major issues at the 1999 National State Long Term Care Ombudsman Training Conference. The poster project includes ombudsmen in ten states collecting information on how the posters are being utilized.

While ombudsmen, for the most part, want to carry out these responsibilities, it needs to be understood that every special project undertaken by an ombudsman takes time away from their day-to-day work with residents. It is this regular contact with residents that is essential to successful ombudsman efforts. The Presidential Initiative is one of the simpler initiatives to implement because there is a national ombudsman structure in place.

Three things are needed:

1) Reauthorization of the Older Americans Act including the current ombudsman language to continue the programs focus on resident and systemic advocacy; 2) substantial funding so that ombudsman programs in every state can meet the Institute of Medicine recommended requirements of one professional ombudsman per every 2,000 residents; and 3) a strong Ombudsman Resource Center that is able to meet ombudsman training, technical assistance and research needs.

**NCCNHR calls on HCFA and Congress** to find new ways to support and strengthen the involvement of family members and citizen advocates.



## National Campaign to Increase Awareness on Prevention of Malnutrition & Dehydration

Malnutrition and dehydration are two of the many crucial and distressing issues in nursing home care. NCCNHR recognized this when we began our own campaign against malnutrition at our 1997 Annual Meeting with the keynote presentation made by Dr. Jeanie Kayser-Jones, a nurse anthropologist at the University of California, San Francisco.

It was during that meeting that NCCNHR successfully encouraged the Senate Special Committee to organize a pivotal forum on this topic. Dr. Kayser-Jones provided solid research findings that shows serious neglect of residents at mealtimes. This was followed by an alarming hearing on the extent of malnutrition and dehydration in California nursing homes - a discovery first made public by consumer advocate, Ila Swan, who has assisted this Committee in previous work.

Undernourishment remains a major, preventable problem; therefore, the work done by the Nutrition Screening Initiative and the American Dietetic Association is particularly valuable as a vehicle for public education. NCCNHR would like to see other professional groups step forward and lead similar efforts on substantial nursing home care issues. The complex problems in long-term care can best be identified with leadership and involvement by experts in particular areas, like what happened regarding nutrition. If caregivers work with HCFA from the beginning of program planning, they are more likely to be predisposed to implementing solutions. HCFA, instead of distributing the Nutrition Alerts is trying them out in ten states. The money for this could be better spent on implementation and support for a product already endorsed by all stakeholders.

This year, Dr. Kayser-Jones will return to the NCCNHR Annual Meeting to give the keynote presentation on dehydration. Her message, once again, is that staffing, especially the lack of it, is the root cause of this problem.

Since the issues of malnutrition and dehydration couple so directly with nursing home staffing, it is noteworthy that the Senate Committee on Aging is willing to help move this issue forward by hosting a forum on nursing home staffing during this year's NCCNHR annual meeting, November 3, 1999.

NCCNHR is pleased that the Administration heard consumer arguments against legislation allowing nutrition/hydration assistants. While NCCNHR understands the desire to take action to prevent malnutrition and dehydration, the lack of staff is a 24 hour problem, not just a mealtime problem.

Time and time again, when family members, residents, ombudsmen, advocates, workers and others are asked what is the most serious issue to tackle in nursing homes, **staffing is the answer**.